Maximizing Independence Through Assistive Technology and Durable Medical Equipment: An Analysis of Critical Issues

October 1999

A Report from the Governor's Commission on Mental Retardation

Maximizing Independence Through Assistive Technology and Durable Medical Equipment: An Analysis of Critical Issues

The Commonwealth of Massachusetts

GOVERNOR'S COMMISSION ON MENTAL RETARDATION

The Commission is especially grateful to Mari-Lynn Drainoni and Bill McIlvane for their invaluable assistance and expertise in creating the overview for this report.

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A Description of Definitions of Medical Necessity for Several States

The **Rhode Island** statute incorporates prevention, treatment of condition, and cost-effectiveness into its definition.

> The term "medical necessity" or "medically necessary service" means medical, surgical, or other service required for the prevention, diagnosis, cure or treatment of a health related condition including such services necessary to prevent a decremental change in either medical or mental health status. Medically necessary services must be provided in the most cost effective and appropriate setting and shall not be provided solely for the convenience of the member or service provider.

Notably, **Minnesota's** definition does not include the criteria of cost-effectiveness in the determination of eligibility. This definition lists "prevention" as a separate health service. Minnesota's definition is also unique in that it specifically encompasses the care of mothers during pregnancy:

> Medically necessary means …a health service that is consistent with the Enrollee's diagnosis or condition and: is recognized as the prevailing standard or current practice by the provider's peer group; and is rendered in response to a life threatening condition or pain; or to treat an injury, illness or infection; or to treat a condition that could result in physical or mental disability; or to care for the mother through the maternity period; or to achieve a level of physical or mental function consistent with the prevailing community standards for diagnosis or condition; or is a preventive health service defined under Minnesota Rules, Part 9505.0355.

Connecticut's statutes contain two definitions: one for "medical appropriateness," and one for "medically necessary." The definition of medical appropriateness addresses cost-effectiveness and accepted standards for treatment. It also recognizes the appropriateness of the medical setting (as does Rhode Island's definition) and the timeliness of healthcare delivery. The definition of medical necessity focuses on the prevention and treatment of illness or injury. The Connecticut statute also specifically refers to "mental illness" as separate from "medical condition."

Medical appropriateness means health care that is provided in a timely manner and meets professionally recognized standards of acceptable medical care; is delivered in the appropriate medical setting; and, is the least costly of multiple equally effective, alternative treatment of diagnostic modalities.

Medically necessary means health care provided to correct or diminish the adverse effects of a medical condition or mental illness; to assist an individual in attaining or maintaining an optimal level of health; to diagnose a condition; or prevent a medical condition from occurring.

Preface

"…I know if I don't have a wheelchair for somebody, and her positioning is bad, and she ends up with aspiration pneumonia [and is hospitalized]…that surely is going to cost them more…than it is to get a proper seating device for that person." Beth Gray-Nix, OTR

"There's never been so much potentially available to profoundly physically challenged people: molded custom made chairs, systems of pressure relief, systems of postural support, means to move, switch technology, pressure mapping, etc., fabrics and substances designed to the individual needs. The irony is a large number of mentally retarded people are forced to use systems that are inadequate and meet their needs only poorly." Susan Rushfirth, RPT

Advances and innovations in technology enable millions of Americans with disabilities to enjoy increased independence, mobility, and communication. For many persons with disabilities, including those with mental retardation, assistive technology (AT) and durable medical equipment (DME) are essential in order to accomplish daily tasks. The Governor's Commission on Mental Retardation undertook a series of activities in 1998-1999 to understand the extent to which persons with disabilities had access to effective assistive technology and durable medical equipment. This effort was organized by the Commission's Task Force on Quality Care that focuses on the health and safety of persons with mental retardation.

We note at the outset that we found the publicly supported system by which assistive technology and durable medical equipment is financed and administered to be fraught with problems. First, there are many people in the Commonwealth who have dire need for a variety of different types of durable medical equipment and who experience unnecessary delays, denials, and even injury because of our system's inability to meet their legitimate needs in a timely and responsive fashion. Second, the absence of clear standards for what constitutes a "medical necessity" promotes the appearance (if not the reality) of inconsistent, and at times, arbitrary decisions that undermine public confidence in the fairness of both the public and privately-funded health care systems. Third, there is a degree of frustration, and indeed outrage, among many users of durable medical equipment and their care providers with the sluggishness of the system in meeting predictable and unarguable needs. Fourth, some problems involve the differential access to technology and equipment, in particular among persons who live in skilled nursing facilities and rehabilitation hospitals. Finally, other problems reflect a general lack of awareness among human service personnel about the potential benefits of assistive technology and durable medical equipment to make substantial differences in the quality of life of persons with disabilities, including those with mental retardation.

The issues researched and the information provided through focus groups and the Governor's Commission public hearing are not unique to persons who have mental retardation. Indeed, they affect a wide range of people with disabilities. Because of the importance of technology to the enhancement of the life opportunities for persons with many types of disabilities, this report will focus on the system as a whole, not narrowly on the needs of persons with mental retardation. The critical issues will be addressed in five sections:

- Introduction to Assistive Technology and Durable Medical Equipment
- Overview of Funding Mechanisms
- Analysis of Critical Issues
- Review of Themes from the Public Hearing held May 11, 1999 at the State House, Boston
- Recommendations by the Governor's Commission on Mental Retardation.

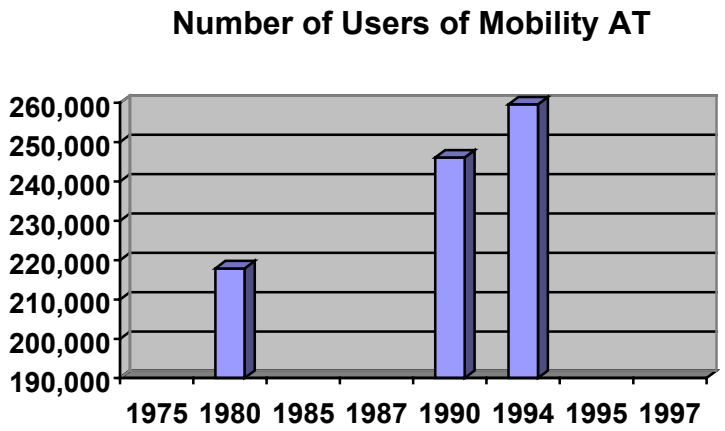
We hope this report will spark new initiatives that are responsive to these challenges and that will bring public programs' willingness to assist people with disabilities more in line with our capacity to do so.

I. Introduction to Assistive Technology and Durable Medical Equipment

A. Increase in Numbers of Persons with Disability

The proportion of Americans living with disabilities has risen significantly over the past 25 years. In many ways, people with disabilities are now the largest and fastest growing "minority" group in the United States. Depending on what definition is used, estimates of the number of people with disabilities range from 35 to 70 million. The U.S. Census Bureau concludes that one in five Americans has some kind of disability, and one in ten has a severe disability (Census Brief, #5, 1997). Research suggests that there are two distinct trends that account for the rise in number of persons with disabilities: a gradual but significant rise in the number of persons who become disabled through advancing age; a second, smaller but more rapid increase in the number of children and young adults who are reported to be disabled.

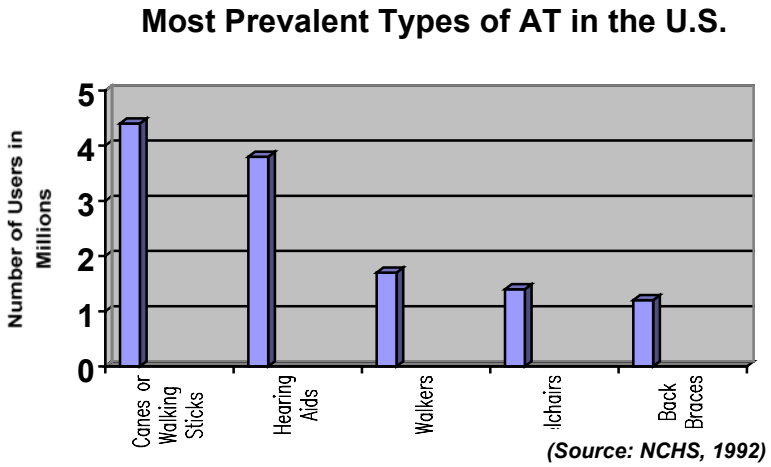
As one would expect, rising levels of disability are associated with an increase in assistive technology use. Between 1980 and 1990, the number of persons using anatomical or mobility assistive technology devices increased at a more rapid rate than the general population. Indeed, wheelchair use increased more than 90 % in this single decade.



(Source: NCHS, 1996)

5.3 % of the non-institutionalized population, more than 13.1 million persons, use assistive devices including canes, hearing aids, walkers, wheelchairs, and back braces (Laplante et al., 1992).

B. Overview of AT



Assistive technology is the term used to describe devices that help people compensate for functional limitations and enhance and increase learning, independence, mobility, communication, environmental control and choice. AT may be appropriate for individuals of any age and level of functioning. An important component of AT design is ease of mastery and use. Such technology may help the user communicate with others, engage in recreational and social activities, learn new skills, obtain work or work more effectively, and control his/her environment to a greater degree than would be possible otherwise. In short, effective AT increases independence and enhances quality of life. A description of several categories of AT follows.

Communication. For a person who cannot communicate vocally, technology can substitute as a voice for the user. Examples include automated speech synthesizers and computerized methods of interpreting eye movements if motor challenges preclude touching a communication board. There is also a growing use of assistive technology with infants and young children, particularly with communication devices being introduced to facilitate early language development.

Environmental Control. Devices to control the environment are important to people with severe or multiple physical disabilities and/or cognitive disabilities. Examples include mechanical, automated, or computerized systems for environmental control or teaching non-human animals such as Cebus monkeys to assist persons with physical disabilities. Assistive technology may allow a person to lock and unlock doors, to control appliances, heating and cooling, home entertainment and learning systems.

Activities of Daily Living. Technology assists people with disabilities to successfully complete everyday tasks of self-care. Examples include devices that assist a person with memory difficulties complete a task or follow a certain sequence of steps in such activities as making a bed or taking medication, homes designed to use technology to assist a person to become more independent, and computer programs or other technology that help a person to shop, write a check, pay the bills, or use an ATM machine.

Employment. Employers are making the workplace more accessible to people with physical and/or cognitive challenges. For example, an audiotape can be used to prompt a worker to complete each task in a job. For individuals who have difficulty with spoken instructions, videotapes or computer-presented video can be used to provide instructions. For an individual with limited or no use of his/her hands, a voice-activated computer provides assistance with work to be done.

Sports and Recreation. Computerized games can be adapted for the user with physical limitations. Specially adapted sports equipment is available to compensate for functional limitations.

Legislation—the Tech Act and its Amendments

In 1988, Congress enacted PL 100-407, the Technology-Related Assistance for Individuals with Disabilities Act (also referred to as the Tech Act). Through this Act, Congress called for the following initiatives: increased awareness of AT needs for individuals; increased awareness of policies and procedures that ensure or prevent access to AT; improved availability and funding for AT; improved knowledge of AT; and more collaboration among state and private agencies that provide AT services and equipment. While the chief purpose of this initial legislation was to fund state developed programs that better addressed the AT needs of persons with disabilities, the Tech Act also contained a strongly worded statement of the role of people with disabilities in our society:

> Disability is a natural part of the human experience and in no way diminishes the right of individuals to live independently; enjoy self-determination; make choices; pursue meaningful careers; and enjoy full inclusion and integration in the economic, political, social, cultural, and educational mainstream of American society (29 U.S.C. 2201 [a][1]).

In 1994, the Tech Act was amended through PL 103-218. This amendment strengthens the goals of the original act and also addresses the importance of systems change and advocacy. PL 103-218 emphasizes the need to overcome barriers for rural and underrepresented populations; empowerment, choice, and control for people with disabilities; and acquisition and delivery of AT for children as well as adults. In

addition, the law also requires that states devote a specific amount of funding to their protection and advocacy agencies. The specific mandates of the law are as follows: Title I of the Act ensures ongoing financial assistance to states to develop and maintain programs that increase awareness of and access to AT. This funding can be used to enhance public awareness, advocacy, and policy development. Title II identifies national funding sources for AT for training and the development of a national classification system for AT devices. Title III provides federal grants to establish alternative funding mechanisms such as low-interest loan funds, loan insurance programs, and partnerships with private entities to help individuals gain access to AT.

C. Overview of Durable Medical Equipment

Durable Medical Equipment refers to products that can be used over an extended period of time and are designed to fulfill a **medical need**. When considering DME, the focus is often on wheelchairs, but DME also includes special beds and devices that assist with personal care and mobility. The boundary between AT and DME is sometimes unclear. One way to understand DME is as a subset of AT—that form of AT which is "medically necessary." Both AT and DME help individuals overcome functional limitations and increase independence. Like AT, DME may also be appropriate for individuals of any age and level of functioning. Unlike many types of AT, however, DME is not generally useful in the absence of illness or injury.

Focus On: Innovation in Wheelchair Design

The history of wheelchair design is a history of innovation by wheelchair users. Early in the 20th century, wheelchairs were bulky and designed predominantly for institutional or home use. Wheelchairs were made of wood and wicker, weighing as much as 90 pounds. They were too wide to get through most doors and could not be easily lifted or transported. There was no ability to self-propel such a wheelchair; constant assistance by an "able-bodied" person was required. In 1918 a man named Herbert Everest was disabled through a mining accident. He asked an engineering friend, Harry Jennings, to design a lighter weight chair. Then, in 1932, they invented a folding chair. Their company Everest & Jennings subsequently dominated the wheelchair market for the next fifty years (Shapiro, 1994).

In 1978, Marilyn Hamilton, an active and athletic woman, crashed her hang glider. She became paralyzed and quickly became disillusioned with the prospect of her life in a conventional wheelchair. She commissioned a new type of wheelchair made of the same lightweight but strong aluminum tubing that was used for hang-gliders. Upon completion, this chair weighed a mere 26 pounds, and the Quickie wheelchair was born. In 1984, a folding version of the chair was designed, and soon hundreds of thousands of people with physical disabilities sought lightweight chairs for everyday use (Shapiro, 1994).

An important component of DME is individual fit and modification, as well as ease of use. DME must be supplied and modified as needed to support body changes including changes in level of functioning and growth. Ease of repair, replacement, and modification are vital to ensure maximum independence for individuals with disabilities. There are two major categories of DME, items that assist with mobility and self-care.

Mobility. For a person who does not walk, wheelchairs and mobility aids are critical. Some types of mobility aids include:

- manual and power wheelchairs (some individuals require both)
- canes, crutches and walkers with attachments
- traction frames, stands and equipment
- belts, harnesses and other cervical and pelvic devices to allow maximum mobility
- other types of mobility systems such as wheelchair cushions and accessories, hand controls, sip and puff mouthpieces and control boxes, footplates, footrests, wheel accessories, and battery chargers.

Self-Care. DME assists people with disabilities to successfully complete everyday tasks of self-care either independently or with assistance. Examples include shower chairs and devices that allow a person to use the toilet independently or with limited assistance.

The rise in the number of people with disabilities, especially those with acquired disability have fueled the creation of many innovative designs and new products. However, the ever-increasing number of consumers of AT and DME has also meant that current funding is fundamentally inadequate. The next section of this report will review several of the current funding mechanisms.

I. Overview of Assistive Technology and Durable Medical Equipment

A. Increase in numbers of persons with disability The proportion of American living with disabilities has risen significantly over the past 25 years. In many ways, people with disabilities are now the largest and fastest growing "minority" in the United States. Depending on what definition is used [see appendix], estimates of the number of people with disabilities range from 35 to 70 million. The U.S. Census Bureau concludes that one in five Americans have some kind of disability, and 1 in 10 have a severe disability (Census Brief, #5, 1997). Research suggests that that there are two distinct trends that account for the rise in persons with disabilities: a gradual but significant rise in the number of persons who become disabled

through advancing age; a second, smaller but more rapid increase in the number of children and young adults who are reported to be disabled.

As one would expect, rising levels of disability are associated with an increase in assistive technology use. Between 1980 and 1990, the number of person using anatomical or mobility assistive technology devices increased at a more rapid rate than the general population. **Insert chart 1** Indeed, wheelchair use increased more than 90 % in this single decade. 5.3 % of the non-institutionalized population, more than 13.1 million persons, use assistive devices including canes, hearing aids, walkers, wheelchairs, and back braces (Laplante et al, 1992.). **Insert chart2.**

Data about utilization specific to utilization is not available. However, there is some information regarding the needs of those who receive services from the Department of Mental Retardation (DMR). Many persons who have mental retardation have secondary conditions as well. Among current DMR service recipients, xx have vision impairement, yy have hearing impairment. Perhaps most significantly, nearly 10% have mobility which is supported through use of Durable Medical Equipment (canes, walkers, wheelchairs).
Insert Chart 3

B. Overview of AT

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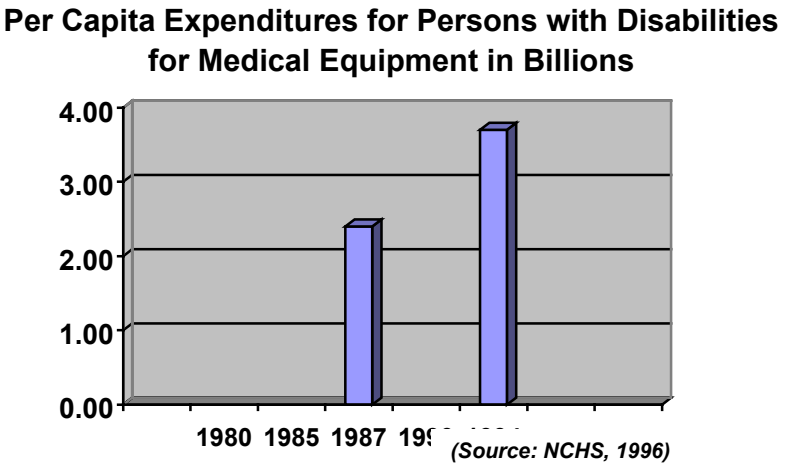
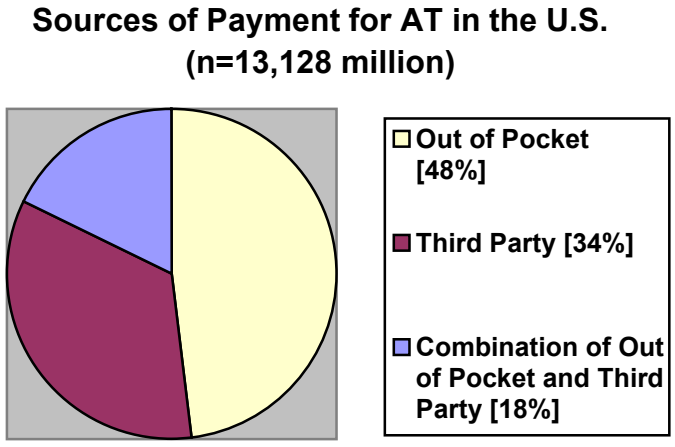
The rise in the number of people with disabilities, especially those with acquired disability have fueled the creation of many innovative designs and new products. However, the ever-increasing number of consumers of AT and DME has also rendered current funding fundamentally inadequate. The next section of this report will review several of the current funding mechanisms.

II. Overview of Funding Mechanisms for AT and DME

Without doubt, there are significant costs attached to Assistive Technology and Durable Medical Equipment. As the number of AT and DME users increases and the variety of technology expands, so do the national expenditures for such devices. In 1993, more than $ 3.7 billion was spent on medical equipment alone (not including the non-medical AT).



Spending for all types of AT and across all age groups has increased rapidly in the past 20 years, and wheelchair use has grown astronomically, increasing by over 90% between 1980 and 1990 (NIDRR 1992). The 1990 National Health Interview Survey on Assistive Devices (NHIS-AD) reveals rich information about cost and utilization patterns for U.S. residents who rely on AT and DME. Significantly, this survey found that individual users and their families are the **single largest payers** of AT and DME (LaPlante, Nearly half (48%) of people who use AT say that



(Source: NCHS, 1992)

they or their families paid for the items with no assistance from third parties. Another 8% said that they got their AT through a gift or for no payment. Also significant, more than 2.5 million persons, or about 1% of the U.S. population, have an unmet need for AT. The reason given most often (60%) for not having such devices is that

people cannot afford to purchase them. Similarly, a 1998 report of a survey of National Arc members (n=1218) reveals that the most frequent funding source for AT was personal funds (Wehmeyer, 1998). No data are available on utilization patterns specific to Massachusetts.

This section of the report will review some of the funding mechanisms for Massachusetts residents who rely on AT and DME. [This information is based on the 1998 handbook developed by the Massachusetts Assistive Technology Partnership entitled, "Assistive Technology: A Basic Training Manual."]

A. Funding for Children

Several funding sources exist that are designed to serve specifically children. The **Department of Public Health** (DPH) has two funding streams that address the AT needs of children with disabilities. Early intervention (EI) provides one type of funding. EI serves children from birth to age three who have disabilities or have been determined to be at risk for developing a disability. While providing developmental, therapeutic, and educational services, infants and young children enrolled in EI programs are eligible for AT and related services. Also through DPH, the Hearing Aid Program for Children provides financial assistance for hearing aids for children and adolescents.

Chapter 766 is the Massachusetts Special Education Law that guarantees free and appropriate education in the least restrictive environment for school-aged children. Children who have been determined eligible for special education services participate in an educational evaluation which results in the development of an individualized education plan (IEP). A team that generally includes the student, parents, teachers, therapists, and advocates creates the plan. If the team recommends that AT would benefit the student, it is to be incorporated into the IEP. The local school district is required to provide all AT written into the IEP. Third party benefits or insurance coverage can cover the cost of the item if the parents agree to use this coverage, but parents are not required to do so. In addition, children with disabilities are often covered by one of the MassHealth products funded by the Massachusetts State Medicaid (DMA) plan. This coverage is reviewed in detail later in this section.

B. Funding for Adults

Funding streams for adults with disabilities come from very diverse sources. The funding mechanisms for AT and DME for adults use public as well as private monies and have been created at both the federal and state level. The resources described below include Social Security, the Massachusetts Rehabilitation Commission, the Department of Mental Retardation, and three types of health insurance.

Anyone who receives Social Security Disability Insurance (SSDI) or Supplemental Security Income (SSI) can obtain **work related AT** through a work incentive program if the equipment enables the recipient to find or maintain employment. The Impairment Related Work Expense (IRWE) and the Plan to Achieve (PASS) are work incentive programs for people whose primary disability is not blindness. The IRWE (available to both SSI and SSDI recipients who are already employed) is money that is set aside from income to pay for a broad array of equipment or services that are needed to support an employee at work. For example, for a person to get out of the house and go

to work, he may need bathroom modifications, a ramp, transportation, or personal assistance. The four basic requirements of the IRWE equipment are: 1) purchased by the beneficiary, 2) non-reimbursable by other funding sources such as public or private insurance; 3) enables the person to work; 4) related to the person's disability.

The PASS program enables SSI beneficiaries to set aside income to purchase equipment and services and keeps income considered for SSI eligibility below the maximum allowed before a reduction in benefits. These set-aside funds can be used for AT, education or any other item or service that would enable the person to achieve vocational independence. The PASS and IRWE programs are similar in that they both promote employment, but the PASS plan is more structured and time-limited (it cannot exceed 48 months). The IRWE sustains employment over a long period of time, whereas the PASS program provides a short-term opportunity for growth and maximal independence. A separate account must be established for PASS plan funds, and payments made into the account must follow a predictable schedule. This plan must be documented and approved by the Social Security Administration.

As one of the largest purchasers of AT for individuals with disabilities, the United States **Department of Veterans Affairs** administers veterans benefit programs and may pay for medical and home care, disability compensation, vocational rehabilitation, pensions for veterans, and home and vehicle modifications. Assistive technology can be wholly or partially funded if included in a veteran's rehabilitation plan.

On the state level, the **Massachusetts Rehabilitation Commission (MRC)** also provides assistance with AT to eligible individuals when AT needs are documented in their Individualized Work Rehabilitation Plan. MRC can also assist with adaptive housing and vehicle modifications. Qualified individuals are aged 16 or older, although transition planning from school to employment can begin at a much earlier age.

A variety of services including **non-work related AT** are available through regional Independent Living (IL) Centers in Massachusetts, which are also funded through MRC. Funding is primarily used for home and/or vehicle modifications. The goal of IL Centers is to foster self-sufficiency and autonomy. Individuals with disabilities who are not receiving vocational rehabilitation services can apply for funding through their local IL Centers. In some cases, an individual who receives vocational rehabilitation can secure funding for AT through an IL Center.

The **Department of Mental Retardation** is the state agency that funds services to adults with mental retardation who are 18 years or older, as well as families who need help supporting their children with mental retardation and/or developmental disabilities who live at home. The DMR provides an array of family supports that are tailored to meet individual needs. This flexible funding can be used for services in the workplace, home or in the community, or for assistive technology.

Focus On: SHARE Foundation

SHARE Foundation has made major advances in communication technology for people with disabilities since it was established in 1983. The organization has developed aids such as Braille modified television controls and telephones, but its chief focus has been adapted computer systems. These systems enable people with disabilities that impair their communication skills to write and speak using a computer. Systems like these have enabled SHARE to help hundreds of people with disabilities, and the demand continues to grow.

Les Cory and Phil Viale, who were inspired by Linda Texceira, a woman with cerebral palsy, founded the organization. Linda's disability limited her ability to communicate her thoughts, but she was able to follow a letter board with her eyes. A computer system was adapted for Linda so that she could control it with a head switch. Linda follows the cursor with her eyes, and makes letter and word selections by using the switch. This information is then communicated verbally through a voice synthesizer. Like all personal computers, written work can be saved or printed, which has enabled Linda to begin writing a book.

SHARE's membership and organization has grown considerably since its founding. In 1987, SHARE joined the South Eastern Massachusetts University's Center for Rehabilitation Engineering, which has further enabled this expansion.

Home and Community Based Waiver

One federal funding stream that the Commonwealth has not used for assistive technology is the Home and Community Based Waiver (HCBS). These waivers, which the Health Care Financing Administration (HCFA) grants in order to promote community based services for individuals who would previously be served in institutional settings, have allowed states to develop community based programs with federal funds nearly equal to those that are paid for facility based services. Forty-one states currently include AT and/or specialized medical equipment in their waivers [see table in Appendix 1]. Although it is not clear why Massachusetts has not sought HCBS funding for AT, one possibility is that DME is already part of the Medicaid State plan, and the need for such expansion was not anticipated. Given the plethora of very valuable non-medically necessary technology and the increase in the number of AT users, it might now be wise to amend the waiver. There are at least two vital criteria for evaluating such an amendment. First, this should be a true expansion and not a cost shift from DMA to another agency. Second, it would be most beneficial to include other disabilities and not solely mental retardation.

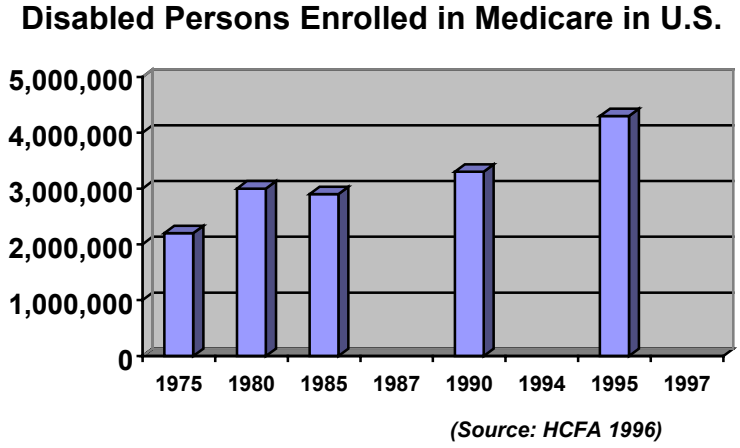
Many types of **health insurance** fund durable medical equipment. The individual will typically have to demonstrate that the item will prevent, cure, alleviate, or prevent the worsening of a medical condition. The item or service must also be considered an accepted and established treatment for the particular conditions by professionally recognized standards. The following section reviews several types of insurance coverage.

Private Insurance

Private health insurance can be a source of funding for assistive technology or durable medical equipment. Some policies cover such rehabilitative services and devices as DME, or speech or occupational therapy. An individual who advocates for funding of AT must prove that the technology is "medically necessary," and this term varies in its definition for each carrier. This is particularly challenging when a person has more than one type of insurance. Another difficulty with private insurance is that the allowables for DME are so small—sometimes a cap as low as $1500 per year or $2500 lifetime benefit—that even moderately expensive equipment cannot be funded. DME users at both the focus groups and the public hearing frequently expressed their frustration with the low caps on DME through their insurance carriers.

Medicare Coverage

Because the largest sector of the population with disabilities is persons over the age of 65, it is to be expected that Medicare is the largest single payer of DME in the nation.



Although Medicare is generally associated with elder care, the program also serves 4.2 million people with disabilities who are below 65 years of age. People with disabilities qualify for Medicare coverage through Social Security Disability Insurance after a two-year waiting period, or through End Stage Renal Disease (ESRD) after their private

insurance runs out. Another way people qualify for Medicare —and this is most common for people with a developmental disability—is to be a disabled dependent of a retired, deceased, or disabled worker.

By regulation, Medicare covers DME when it is necessary and reasonable for the treatment of an illness or injury, or to improve the functioning of a "malformed body member." This equipment must be medical in nature and not primarily for "lifestyle" use. Medicare will deny payment for equipment that is not solely medical in nature (i.e. it is generally not useful to a person without a medical condition). Therefore equipment that may be crucial to the patient's well being can be denied if it is considered a comfort or convenience item. In addition, Medicare standards are narrowly focused on home-based use and require substantiated evidence of bed or wheelchair confinement. Thus equipment that would be beneficial for accessing the community can be denied. This is particularly true for wheelchairs that are made of lighter weight (and more expensive) materials. This policy has been further clarified by HCFA. "…Medicare will only pay for standard items for beneficiaries unless the beneficiary's physician prescribes and justifies lightweight materials or customized items on medical grounds. Thus, Medicare will not pay for items that accommodate active lifestyles, such as items manufactured of lightweight materials or with custom features."

Medicare policy does not have a standardized definition for medical necessity. Instead, coverage is based on specific criteria for each *piece* of equipment used in the home. For example, Medicare coverage of a manual wheelchair is based on a substantiated claim that the medical condition results in confinement without the use of a wheelchair, and that the primary reason for the wheelchair is non-lifestyle use. Lifestyle use includes going to work and accessing the community to perform daily activities. Coverage is also based on the cost-effectiveness of the equipment. For instance, coverage for a manual wheelchair is met by the following criteria:

> A wheelchair is covered if the patient's condition is such that without the use of a wheelchair, he would otherwise be bed or chair confined….This basic requirement must be met for any wheelchair. An upgrade that is

> beneficial primarily in allowing the patient to perform leisure or recreational activities will be noncovered. Payment will be based on the allowance for the least costly medically acceptable alternative.

Similarly, a power wheelchair is covered when all of the following criteria are met:

> The patient's condition is such that without the use of a wheelchair the patient would otherwise be bed or chair confined, and the patient's condition is such that a wheelchair is medically necessary and the patient is unable to operate a wheelchair manually, and the patient is capable of safely operating the controls for the power wheelchair.
>
> If documentation does not support the medical necessity of a power wheelchair, but does support the medical necessity of a manual wheelchair, payment is based on the allowance for the least costly medically appropriate alternative. Options that are beneficial primarily in allowing the patient to perform leisure or recreational activities are not covered.

Over the past two decades, thousands of citizens with mental retardation and other developmental disabilities have been enrolled into Medicare. It is estimated that over 70% of DMR service recipients have both Medicare and Medicaid. This effort, which was intended to facilitate federal funding for health care costs, has had the unintended consequence of limiting access to many different types of services including DME. Although one might think that having both forms of health insurance would enhance access to medically necessary equipment and supplies, in actuality, it limits access. Because of its narrow focus on "in the home" needs, Medicare routinely denies equipment that Massachusetts Medicaid (Division of Medical Assistance, DMA) would approve. This would include equipment that is used only part of the time. Because all claims must go through Medicare first, these denials delay payment to DME suppliers and can thus delay or even deny access to necessary equipment to consumers. In the recent past, these denials were not insurmountable. At one point, if an item appeared to fulfill the requirement of "medical necessity" by DMA standards but was needed primarily for out of home use, the DME supplier would simultaneously request prior approval from DMA and file a claim with Medicare seeking a denial of the claim. However, this *pro forma* "seeking denial" is now unacceptable to DMA. Unisys, the private contractor that processes all DMA claims, will refuse payment on any claim that has been processed to Medicare seeking only a denial.

Indeed, Unisys can require that the vendor go all the way through the Medicare appeals process—a wait of a year or more—to demand payment even when it is clear that Medicare will not pay for certain piece of equipment.

Two examples of this type of restriction was brought to the attention of the Commission by Adria Hodas, a master's level nurse who coordinates health care for TILL, Inc., a large provider of DMR funded services. She writes:

> *"GS is a man with severe mental retardation, blind and with some deformities of his legs so that he has limited mobility…he is not able to walk long distances, especially on uneven surfaces….He had an old wheelchair which was falling apart, so we initiated the process to obtain a new wheelchair for him….At that point the vendor inquired about insurance and was given both the Medicare and Medicaid numbers….Before the order could be processed, GS [the consumer] had to contact Medicare to determine if according to their records he was in possession of a wheelchair and if so, there had to be clear justification as to why a new one was required….One of the [vendor's] concerns was that the report indicated that the primary use was for out of the home and Medicare would only approve a wheelchair for use in the home. Not only did GS not need to use a wheelchair in his home, but it was clinically inappropriate to have him use it where he did not need it. The wheelchair was needed for recreation, socialization and to attend medical appointments. At this point the report was rewritten by the PT and resubmitted to the physician for review and signature. Over four months had gone by, and we had yet been able to submit the request to Medicare and Medicaid….Finally, in conversation with another vendor we were offered another donated wheelchair. This one was not measured to his size, but was adequate so we gratefully accepted the wheelchair and ended the process."*

> Ms. Hodas shared another vignette with the Commission, noting:

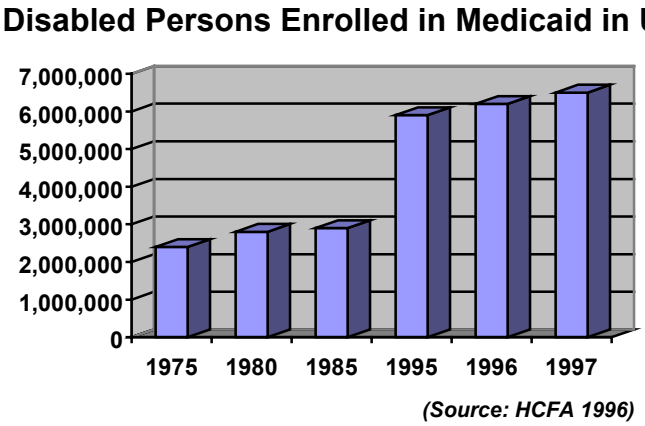
> *"A woman with severe mental retardation, seizures, limited ambulation and recovering from fractures of the tibia and fibula. She needs a wheelchair for long distances out of the home or day program, but does well with a walker and staff assistance at home and in the day program. Because she has Medicare, she was denied approval for the purchase of the walker because they will not pay for a person to have both a walker and a wheelchair. Because they denied it, Medicaid would not pay for it. The happy ending to this story is that her family was able to afford to purchase the walker for her, and she is doing well with it."*

While any effort made to maximize federal funding for health care is prudent and even laudable, this unintended consequence of enrolling persons with disabilities into Medicare is nothing short of tragic. To functionally prohibit citizens' access to medically

necessary equipment is unconscionable and, more importantly completely, rectifiable. Relatively simple bureaucratic reforms that would promote simultaneous billing to both agencies and prompt payment would eliminate much of the burden.

Medicaid Coverage

Medicaid is the primary federal program providing health and long-term care to poor families, the elderly, and people with disabilities. Of the 36 million people covered by Medicaid, 4.9% are people with significant disabilities (HCFA, 1996). Federal Medicaid spending has increased significantly over the past two decades.



People who receive SSI meet the federal eligibility requirements for Medicaid, and states can determine additional eligibility requirements and are allowed to provide benefits to additional groups of individuals. States that meet the federal eligibility guidelines receive federal matching payments ranging from 50% to 80%. There are certain mandatory Medicaid services. DME is not one of them. Massachusetts does include DME in its state plan and receives 50% federal reimbursement.

Medicaid will not pay a provider for services or equipment that are not determined to be "medically necessary." During the Governor's Commission hearing, one testifier noted that the limitation of "medical necessity" is contradictory to a fundamental objective of the federal Medicaid law as it was established in 1965. In addition to offering medical assistance on behalf of families, the law states that appropriation is also for "rehabilitation and other service to help [such] families and individuals attain or retain capability for independence or self-care." However, state Medicaid definitions of medical necessity generally do not include the promotion of independence in its criteria for payment. Medicaid's practice of denying equipment or services which address quality of life such as employment and activities outside of the home could be construed as in violation of the original intent of the law.

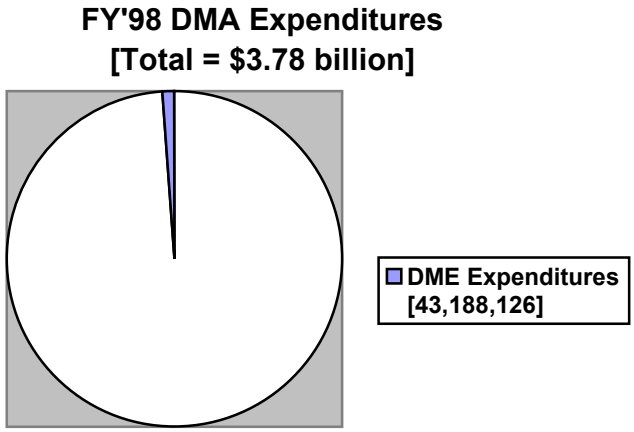
Each state has established its own definition of "**medical necessity**." Although they vary, most definitions share common themes. Generally, these definitions are based on the principles of prevention of illness or injury, treatment of illness or injury, professional recognition of treatment based on a particular condition, and cost-effectiveness of service or equipment. In order for equipment and services to be approved, they must not be investigative or experimental in nature. Nor can they be intended solely for the purpose of engaging in recreational or leisure activities (some statutes use the term "convenience").

States' definitions usually do not contain all of the aforementioned components. For example, the **Massachusetts** definition addresses prevention and treatment of illness or injury, professional recognition of treatment, and cost-effectiveness of the proposed treatment.

> A service is "medically necessary" if it is reasonably calculated to prevent, diagnose, prevent the worsening of, alleviate, correct, or cure conditions in the member that endanger life, cause suffering or pain, cause physical deformity or malfunction, threaten to cause or to aggravate a handicap, or result in illness or infirmity; and there is no other medical service or site of service, comparable in effect and available or suitable for the member requesting the service, that is more conservative or less costly to the Division. Medically necessary services must be of a quality that meets professionally recognized standards of health care, and must be substantiated by records including evidence of such medical necessity and quality.

Examples of other state definitions of medical necessity are available in Appendix 2. Although worded somewhat differently, the states' definitions of medical necessity are similar and include either all or part of the four basic components of prevention, treatment, accepted standardized practice, and cost-effectiveness. In terms of these written regulations, Massachusetts does not differ significantly from other states.

As noted, Massachusetts includes DME in its state Medicaid plan. For each of the last three years, DMA has spent slightly more than $43 million on DME and supplies including mobility systems, oxygen and related products, ventilators, walkers, canes, crutches, splints, enteral products (liquid food), bandages, tapes, gloves and syringes as well as hundreds of other products. This accounts for less than 2% of the total DMA budget. Less than $3 million is spent on power and manual wheelchairs, or less than 1/10 of 1% of its total budget.



(Source: DMA 9/99)

Although individuals and families are commonly the largest purchasers of AT and DME, state and federal funding mechanisms can be utilized to offset some of the costs that many families must incur. Because of the multitude and complexity of the various funding streams, it is important for individuals with disabilities and their advocates to be knowledgeable about which types of sources to access when seeking financial assistance for AT and DME.

How to Get a Wheelchair in Massachusetts If You Have Medicaid

1. The individual goes to the physician and asks him or her for a prescription.
2. The individual then goes to the physical therapist and/or a seating clinic. The vendor's Rehab. Technology Supplier (RTS) and physical therapist will evaluate and fit the individual for the wheelchair.
3. The physical therapist will write a letter of medical necessity.
4. The vendor will get quotes from the manufacturers of the different components to the wheelchair. There is usually a different manufacturer for the frame, the seating, and the electronics. It is not unusual to have five different suppliers for one wheelchair.
5. The information from the physical therapist and physician as well as the pricing information will be mailed to the DMA Prior Approval Unit.
6. A physical therapist, who works for DMA as a consultant, is to review the request within 15 days.
7. The consulting therapist can approve the request, deny the request, or defer the request. Cases of deferral require more information from the patient's caregivers. All decisions are mailed back to the vendor.
8. In the case of deferral, the vendor finds the physical therapist and asks for more information. Nothing can be done until the additional information is sent in to the vendor who will then send it into DMA.
9. If the information is sufficient, the prescription request gets prior approval (PA).
10. The vendor then orders the parts for the wheelchair.
11. When all the parts are delivered to the vendor, the wheelchair is assembled.
12. An appointment is then set up with the physical therapist and the patient for a final fitting.
13. Adjustments are made. Sometimes the wheelchair is returned to the vendor for major changes.
14. Only after the wheelchair is delivered to and accepted by the consumer can the vendor bill DMA.
15. Unisys, a DMA contractor, does the claims processing. Payments are to be made within 30 days; this is rarely achieved. Payment usually takes between 90 and 120 days. Longer is not uncommon.
16. Even though there is already prior approval for the item, Unisys pulls out any claim for equipment that costs over $3000 for a manual review.
17. Payment is made to a vendor on a cost-plus basis. That is, the vendor is paid a 1.4 mark-up over the cost of the chair and its components.

III. Critical Issues in Access of AT and DME

"This is about people trying to live. It's not about a taxi or a TV repair. When our chairs don't work, we don't get out of bed; we don't take a shower. This equipment is crucial to living your life." *—DME User*

"You hate to tell [parents] 'Well, after our assessment, we see that your child could benefit from a switch, or all of this different type of equipment, but you can't have it because there's no money for it.' Sometimes I've got this litany of things I could give to people if they lived in another state, had a different job, or a higher salary."
—Speech Language Pathologist in western Massachusetts

Over the past eighteen months, the Governor's Commission on Mental Retardation through its Task Force on Quality Care has examined access to high quality assistive technology and durable medical equipment by the Commonwealth's citizens with disabilities. The group was devoted to reviewing the care of persons with the most intensive needs and who were challenged in multiple areas. Prior to holding the public hearing, this Task Force interviewed over 20 users of DME and AT through focus groups. In addition, Commission staff met with five vendors of DME as well as with key staff from the Department of Mental Retardation and Division of Medical Assistance regarding the current system. These activities revealed remarkably high levels of frustration among users of AT and DME, their support staff, and clinicians. Users of DME and AT appear to have few avenues for gathering additional information about meeting their needs. Experienced and expert clinicians spoke of hours spent "fighting the system," writing and re-writing letters of medical necessity without clear guidance as to what reviewers need to make a fair decision. Some equipment is nearly two decades old. New equipment goes without routine maintenance and cleaning. As one Task Force member noted: "I learned that assistive technology and durable medical equipment is not frosting on the cake but is the cake itself." This section of the report will review several of the issues that impede access to adequate levels of AT and DME.

Information about Innovation

The lack of awareness and information about new products was reported during the focus groups and site visits. Some clinicians noted that at times they were reluctant to tell a family about a piece of equipment when there was no means for funding that equipment. Others suggested that the different levels of awareness among school based clinicians had a significant impact on access because they were the primary conduits of information about technology to the families. Although the Commission has not heard evidence of this, one wonders about the inherent disincentive of having a clinician who draws a salary from the school system serve as the main information resource about equipment that would most likely be paid for by this same school system.

Cost Effectiveness and Quality of Approved Products

Focus group participants who use AT and DME are fully aware of the costs of their equipment. Many report paying for items themselves or with the assistance of their families. Others who work and have private insurance are frustrated when even basic DME is not adequately covered. As one focus group participant noted: *"My short leg braces were the cheapest ones I could get because that's all my insurance would pay for. And then they break, and I can't get another pair for two years….The plastic is always cracking. They're very cheap. The problem is the low benefits, which leads to a lower quality product. HMO Blue only pays for $1200-$1500 a year."*

Focus group participants report that the balance between cost and quality is not regularly achieved, and they challenged the notion that the cheapest equipment was cost-effective. Among Medicaid recipients, there is a widespread perception that equipment used to be of higher quality that resulted in less frequent repairs and replacement costs. As one person noted: "*I use a walker at home, and it doesn't seem that stable. DMA buys the cheapest quality equipment. To me, if they bought things that could take a beating, it would be better because people will bump into things, and then they break. No way would they break, if they bought quality*." Among older DME users, there was a perception that quality had eroded*: "I think we should focus on quality. When I grew up,*
the quality of the equipment was much better. It was heavier, and sturdier. Now it's just faster, smaller, cheaper." And, *"My greatest difficulty is when things don't work properly. I think it's the quality issue as opposed to the maintenance issue. I had problems with my first wheelchair, and this one doesn't fold very well, and the tires always seem to go flat."* Several focus group participants told frightening stories of having their wheelchairs break down as they were crossing the street or in a deserted area after dark.

Access to high quality medical supplies is also problematic. Two vignettes illustrate the problem: *"I have a night bag, and in the morning I have to do urine drainage. Mass Health and Blue Choice won't pay for the Bard bag (a more expensive but much higher quality bag). The Bard bag is made so that if the bag tips, the urine won't go back up the tube and give me a "pee bath" every morning. This happens with every other bag. How much more expensive could it be? Everyone should have to take a "pee bath" so they know exactly what I'm talking about."* Another participant noted, *"I have very sensitive skin. I can't use the cheaper type of some products because I get skin breakdown. They will only pay for the cheaper kind, and it doesn't work for me. The difference in cost is $4.00. It's devaluing for them to do that. They would rather pay for a hospitalization after skin breakdown than pay for anything preventive."*

Length of Wait for New Equipment and Repairs

Long waits for new equipment and repairs result in frustration, lost time from work, and physical discomfort. All the AT and DME users complained of waits of over three months:

"I put in a request for arm rests on October 22, and I'm still waiting [on January28]."

"I'm still waiting for a new back and a new seat for my manual wheelchair from my supplier…I've been waiting five months now. It is uncomfortable, and I already have one sore. I can't go to another supplier, because then I have to do all that paperwork all over again."

The complaints about the long waits for repairs and modifications led Commission staff to visit with DME vendors. All persons acknowledged that the waits were too long, but they also reported that certain changes in levels of reimbursement and timeliness of payment had reduced their ability to have adequate levels of repair staff available. For example, three common types of repairs are no longer covered at previous levels. Plastic coated hand-rims and armrests are reimbursed at below cost to the vendors. Suspension forks, equipment that functions much like automobile shock absorbers, are no longer covered at all. Significantly, no evaluation of consumer satisfaction or timeliness of repair is completed among those who provide Medicaid approved equipment.

Denials for Basic Items

There was also a myriad of reports that shower chairs are now almost impossible to get prior approval for. Clinicians note with exasperation that they now spend time in discount stores scouting out plastic lawn-type chairs that can fit in a bathtub or shower stall, when a shower chair used to be routinely approved. In another example [see text box on next page] involving a person with mental retardation, a shower chair was approved, but not with the components that would allow her to manipulate it independently. Forty dollars were saved by approving the lower cost chair; $40 for an item that will last at least five years. This apparent inability to balance initial cost with long term cost and independence is at the heart of our interviewees' complaints.

Other complaints were simply mystifying. One focus group participant noted that her raised toilet seat was deteriorating, *"The plastic is cracked and the stuffing is coming out. They told me to go buy my own. This cost me $35-40. I don't have that kind of money, living on an SSI check."* This particular item does not require prior approval. This woman should be able to order a new seat that DMA will pay for. What is particularly heart-wrenching is that this woman had no idea how or to whom she should complain about her access to a fundamental piece of equipment. Both the example of the raised toilet seat that should have

been simple to acquire and the "false savings" on the shower chair highlight the need for a consumer-friendly complaint resolution process. These mechanisms, often called *ombudsmen*, are not designed to adjudicate complaints, but rather to facilitate through information and assistance so that consumers can know where and how to resolve their concerns.

A letter of medical necessity for a shower chair….

To Whom It May Concern:

R. is a 37-year-old woman who currently resides at xxx…with seven other developmentally delayed adults. Her diagnoses include mental retardation, cerebral palsy and paraplegia caused by a fall in 1982. Past medical history includes resolved akasthisia and right knee burn with skin graft. She also has a significant history of skin breakdown on her buttocks with skin grafts in the past. Skin breakdown continues to be an issue with R.

R. is independent in wheelchair mobility indoors and can manipulate the brakes. She transfers to all surfaces via a 2-person lift due to paraplegia. Once she has been transferred to her shower chair, she can independently maneuver her shower chair into the bathroom. She can independently wash her upper body but requires some assistance to thoroughly clean her lower body.

R. needs a new shower chair. She has not had a shower chair of her own since moving to xxx residence and has borrowed one that belongs to a housemate. That shower chair is in disrepair and is unsafe to use at this time. In addition, she should have her own shower chair for sanitary reasons, particularly since she frequently has open areas on her buttocks. An Invacare shower commode chair is recommended, model 6492. This chair's frame, crossbraces, arms and footrest are corrosion-resistant coated. R. needs a shower chair that will last, as she will need to use one daily for the rest of her life.

The Invacare 6492 has the following features:
--2-24" back wheels which will allow for increased independence as she will be able to maneuver the shower chair in and out of the bathroom without staff assistance.
--Secure braking system for safety—the 24" wheels also have a more secure braking system as compared with casters.
--Cushioned U-shaped seat to facilitate access for thorough cleansing. The cushioning is necessary due to skin integrity issues.
--Padded armrests.
--Seatbelt for safety.

R. desperately needs this shower chair to complete her activities of daily living as safely and as independently as possible. Thank you for your careful consideration of this matter.

Sincerely,

Location of Service Restricts Access

Where the consumer lives determines who pays for DME. If a person lives in the community or in a DMR facility (ICF-MR), the typical process of seeking prior approval (PA) is used. In other living situations, including skilled nursing facilities (SNF), acute, chronic, and rehabilitation hospitals, almost all forms of DME are to be provided by the facility. Until a few years ago only "standard" DME such as a basic walker and wheelchair was paid for and provided by these locations. Any item that was "customized" [see text box] would go through the PA process, and if approved, paid for by DMA. Unfortunately, many types of DME that were considered customized five years ago are now considered standard and are to be paid for by the facilities. Specifically, most equipment is now built from a variety of component parts. Most of these individual components could meet the needs of a wide range of consumers and thus meet the current definition of "standard" products. For example, the wheels for a chair might be useful to thousands of users, as could a particular headrest or joystick. But the process of transforming these "standard" components into a functional piece of equipment requires a great deal of time and expertise. Because of the improvement in the manufacture and availability of technology, much of the specialty DME is no longer considered "customized," even though another person could not use it without extensive modification, new parts, and hours of refitting.

Customized Equipment: Durable medical equipment that is made-to-order or adapted to meet the specific needs of a particular patient and that is sufficiently specialized or modified to preclude the use of such equipment by subsequent patients.
106 CMR409.402 (D)

This change in interpretation means that much of the specialty DME is now to be paid for by hospitals and nursing homes. This may be sensible for hospital settings that can receive hundreds or even thousands of dollars per day for care. For a skilled nursing home receiving a little more than $100 per day, funding an expensive piece of equipment is untenable. This burden seems to be particularly onerous for the pediatric nursing homes whose patients have very extensive needs and require frequent changes due to growth and changes in condition. Even more important, it is the patient who suffers because of the frequency with which their DME needs go unmet.

This cost shift from the state agency to the individual facility has resulted in a significant reduction in access based on the person's living situation. Several examples of this difficulty have been brought to the attention of the staff of the Governor's Commission. For example, a rehab hospital in the greater Boston area initially refused to pay for a new power chair for a resident who had lived at the hospital for several years. Noting that the resident was living in the hospital because there was no community settings available, the hospital administrator felt that it should not be responsible for the new wheelchair. This situation was not resolved until a senior staff member of DMA called the rehab hospital's administrator. Another situation is that of a DMR consumer who was a patient at a rehab hospital in northeastern

Massachusetts. He had waited well over a year for his wheelchair, and it arrived only after vigorous advocacy. Because of the intensity and frequency of the advocacy, one wonders how medically necessary equipment is acquired by patients who have no one to advocate on their behalf.

Access to DME in nursing homes is even more difficult because the Medicaid reimbursement for these facilities is so much lower. One example that was brought to the Commission's attention was that of a young man who lives in a skilled nursing facility in the Worcester area. Through his mother's fervent advocacy, he now attends a day habilitation program five days per week. The day program wanted the consumer to use a walker during physical therapy. This request was denied by DMA because the SNF was responsible for the equipment. The SNF would not purchase the equipment because it was not to be used by the facility. This situation was resolved through the gift of a walker by "Pass It On," a charitable foundation that gives donated equipment to persons in need.

Finally, there appears to be confusion regarding the licensing of the DMR facilities. Dever, Fernald, Glavin, Hogan, Templeton, and Wrentham are all licensed as ICF-MR. Thus, almost all DME would go through the PA process and be paid for by DMA not the facility. Unfortunately, some sites are mistakenly identified as chronic care hospitals. Several equipment suppliers have been audited and fined for supplying DME through the PA process rather than billing the facility. This is a long-standing problem and one that needs to be rectified immediately.

Focus On: Pass It On, Inc.

Pass it On, Inc. was established in 1992 as a volunteer-based effort to collect and distribute used medical equipment to disabled individuals in Eastern and Central Massachusetts. The mission of the organization was to assist individuals with disabilities to have the opportunity for greater independence, dignity, and comfort. Since its establishment, Pass it On has donated over 2000 pieces of equipment to more then 1400 individuals and families and sent over $25,000 in surplus equipment overseas.

Equipment is donated to individuals and families who do not have insurance coverage for a product, who cannot pay the insurance co-pay for a product, or who do not have the funds to rent or purchase the item. Equipment that is generally available in large supply, such as walkers, canes, and commodes, are donated more freely. The application process is confidential, and financial information does not need to be submitted.

Although the motives have stayed the same for the organization, it has greatly expanded its services. Recently, the organization has shipped surplus equipment to the international community, supplying poor hospitals in over 45 countries. Recently, the organization began accepting medically related goods like eyeglasses, hearing aids, under garments, bandages, and liquid nutrition supplements. Generally, these products have been donated to nursing homes. On a larger scale, Pass It On, Inc. has engaged in networking with other human service organizations to ensure that individuals receive all services to which they are entitled. Pass it On, Inc., through all of its efforts, has enhanced the quality of life for hundreds of individuals with disabilities.

DMR Assistive Technology Centers

Each DMR Region has some type of Assistive Technology Center. In Central Massachusetts, AT staff are based at two DMR facilities—Monson and Glavin. These technicians serve only the residents of each facility. In the two other DMR regions, facility based AT centers also serve community members with differing degrees of outreach. In western Massachusetts, where there is no DMR facility, the AT Center is freestanding and is open to all. One of the Commission's focus groups was dedicated to learning more about these centers.

These clinicians and designers take great pride in their work and recognize that the number of persons who have mental retardation as well as AT and DME needs is increasing. It was clear that they offer significant expertise and dedication to this population. As one designer noted: "*What makes us successful is the linkage between the clinical and design components. The designers are creative, and the clinicians have the clinical experiences to know what to recommend*." Flexibility of design is another aspect of these AT centers that was raised at the focus groups. Although the funds for supplies are quite limited at the AT centers, regulation or traditional resources to create new AT devices or positioning systems do not confine the designers.

One particularly comprehensive approach is available in the Northeast Region of the Department of Mental Retardation (Region 3). The REACH clinic, which stands for Regional Evaluation and Assessment for Community Habilitation, is available to any person who receives services from this DMR region. This clinic is not limited to assistive technology but offers a full range of clinical assessment. REACH hosts a seating clinic regularly, and the vendor has a tremendous amount of experience with this population having had his training at Lakeville Hospital, a former DPH site for people with chronic illness and disability. Referrals to REACH are made for many reasons including the need for multidisciplinary evaluation by clinicians who are familiar with the needs of persons with mental retardation, an evaluation not covered by insurance, or determination of DMR eligibility.

In the Boston area, the Metro DMR Region (Region 6) offers an adaptive equipment library as well as an AT center that serves community based clients. The equipment loan program fosters independent living and learning for individuals with developmental disabilities. The library was established by the Massachusetts Department of Mental Retardation's Occupational Therapy Department and received its initial funding from the Fernald Corporation.

The library lends books and catalogues as well as over 450 commercial products. These products are engineered towards helping individuals with developmental disabilities perform basic daily tasks, like using the telephone, appliances, and the television. These aids include adapted television remote controls, switch

operated pouring cups, and picture telephones. In addition to providing these resources, the library provides training with the equipment. The library is staffed by an occupational therapist trained in the use of this technology with individuals with developmental disabilities. The staff works to ensure that individuals are properly matched and trained with a product, which then enables them to make educated choices on purchases. Furthermore, the staff also engages in research for new products and innovative strategies for training individuals with developmental disabilities.

Many focus group participants had ideas about ways to expand and standardize these centers so that all persons who receive DMR services (and in some cases beyond) could make use of them. These suggestions include: providing a clearinghouse on resource information and hosting seating clinics with vendors who were particularly competent at fitting wheelchairs for people with developmental needs. Other ideas that were generated during the focus groups were to have these centers be "free-standing" in terms of administration and funding in order for all of them to receive federal grants and charitable donations.

It is clear that the issues surrounding AT and DME are multi-dimensional. Yet even in an overview as cursory as this, the complexity is overshadowed by a single point: AT and DME are crucial to the health and happiness of millions of people with disabilities. Without effective and sufficient access to AT and DME, citizens who rely on such equipment may be unable to perform even some of the most basic activities of daily life. Activities such as taking a shower independently, going to the grocery store or to a medical appointment, or answering a teacher's question in school can become impossible when funding for a shower chair is denied, when a power wheelchair awaits repair, when there is no means to repair a child's communication device. The next section of the report will review the testimony of the Commission public hearing on this topic.

IV. Themes from the Public Hearing

"Speaking as a clinician working in the field, it can sometimes feel like a jousting match between those who are requesting the equipment—the individuals, their elderly parents, perhaps, or the therapists—and those who are facilitating the funding. This is particularly the case when more versatile or customized equipment is requested. There really should be no reason why a severely spastic man, with multiple joint contractures and no sitting balance should have to make a very intricate case for a supportive, reclining bath seat. The reality is that he does, or his representatives do, and the reality is that he can be denied." Susan Rushfirth, RPT

The Governor's Commission on Mental Retardation is required to hold public hearings throughout its tenure. The Commission's Executive Order states: "The subject of such hearings shall include, but shall not be limited to, the quality of the health, safety, and well-being of the Commonwealth's citizens with mental retardation; the quality of publicly funded service available to such citizens; and the extent to which the private sector and the community at large provides opportunities for persons with mental retardation." Accordingly, the Commission's seventh public hearing held on May 11, 1999 at the State House, Boston, was devoted to an examination of access to assistive technology and durable medical equipment. Both oral and written testimony was solicited from over one thousand individuals who have disabilities, their families, providers, advocates, and state agency officials.

The purpose of the public hearing was to seek testimony from clinicians, consumers, and vendors regarding their analysis of the difficulties in obtaining essential technology and equipment. Throughout the public hearing, the Commission heard of situations in which access to fundamentally necessary equipment was limited by lack of awareness of what is available, by procedural patterns that resulted in unnecessary delays in approval, by the absence of clinical standards, and by inadequate funding. The hearing vividly demonstrated the gap between the first hand experience of those who use such technology and the bureaucratic entities of those who provide the funding. This section of the report will review several of the obstacles to access that were described at the public hearing. It will be divided into two sections. The first section will examine the awareness and access issues, and the second will review the administrative and funding issues discussed at the public hearing.

A. Awareness of Assistive Technology and Durable Medical Equipment

Barbara Chandler, Executive Office of Elder Affairs, testified with a particular population in mind: elders who are taking care of their adult children with disabilities. She suggests that both groups could benefit from various forms of assistive technology, noting: "*The issues for these groups are that oftentimes they are not even aware of what assistive technology is, and how it could benefit them. And even when they do become aware, they're not plugged into systems to access that type of equipment."* Sonia Perduta-Fulginiti,

a registered nurse, concurred*: "In my almost a quarter of a century of professional and personal experience with these issues, I believe that it is a fundamental lack of disability knowledge and a blind adherence to disability mythology, stereotyping, and discrimination that lie at the foundation of this funding barrier."*

Access to the Expertise Available through DMR Assistive Technology Centers

During the hearing, Beth Gray-Nix, OTR, described the adapted equipment program housed at Fernald that serves the entire Metro Region. Other clinicians noted the benefit of having access to the AT centers. In written testimony, Adria Hodas suggested that one of the obstacles to access was the need for trained, experienced therapists to evaluate equipment for this population. She noted that such therapists were available at the hospital seating clinics and the AT centers of the DMR facilities.

B. Funding Mechanisms are Either Non-Existent or Inadequate

Assistive Technology. Although the benefit of many forms of assistive technology have been recognized for decades, funding streams to ensure access to such technology still lag behind. Tom Driscoll, from the Massachusetts Assistive Technology Partnership, noted *"...the state is not funding enough assistive technology in the vocational/rehabilitation plan. There's possibly a little line item in there, but there's not enough clout."* Mr. Driscoll also noted that there was an *"unspoken rule"* with regard to service delivery: MRC consumers either get services or devices but not both.

Barbara Chandler reminded the Commission that not only does limited access to AT prevent individuals from returning to the work force, it leads to more out of home placements as well. She noted: *"One of the things that we have been seeing over the last couple years…is that oftentimes the absence of assistive technology can result in the placement, the early placement, of both the parent and the son and daughter with MR. Without that type of help in the home, we're putting tremendous physical and emotional stress on individuals, which results in further deterioration."*

Durable Medical Equipment. Funding for DME is more readily available than funding for AT. However descriptions of problems with funding for DME permeated the hearing. Five topics in this area received much attention:

- Definition of medical necessity.
- The absence of clinical standards by which DME can be evaluated.
- Location of service often impacts access to DME.
- Unrealistically low caps on DME benefits for private insurance are too low.
- Access to DME is often impeded when a patient has both Medicare and Medicaid.

Definition of Medical Necessity

Much of the hearing testimony identified the need to expand the definitions of medical necessity to include more quality of life considerations. In her written testimony, Adria Hodas identified this need by asking: *"Appropriate equipment is essential for personal hygiene, proper positioning to eat to prevent aspiration, seating systems that reduce pressure causing break down, seating systems and other equipment that establish correct alignment to reduce abnormal muscle tone and risk of increasing contractures…but what about the need to have equipment to travel out of home to work, for recreation, to socialize with family and friends and to attend medical appointments? What about assistive technology to make work, communication and recreation possible and fulfilling? These are more quality of life issues, but deeply impact the person's status in society, self-esteem, even mental health."*

Absence of Clinical Standards

DMA regulations do not include clinical standards by which an approval or denial of equipment can be evaluated, and this absence leads to a sense that decisions about equipment have a random quality. Throughout the focus groups, therapists and advocates noted that one could never tell whether a piece of equipment was likely to be approved or denied by Medicaid. As physical therapist Susan Rushfirth noted during the hearing: *"It just seems a little…indeterminate as to why sometimes things are refused, and sometimes why they're deferred, and then, sometimes, rather literally, with only the changing of the couple of sentences, that same report will result in an approval.* In her written testimony, Adria Hodas, concurred: *"Although it may not be intentional there can be a feeling that requests are routinely denied initially, which screens out people who are not willing, able, or knowledgeable to continue the process through appeals. Those people who are persistent have a better chance of being successful, than those who take the denial at face value and assume a 'no' means 'no.'"*

Compounding the absence of clinical standards is the lack of communication between the prescribing therapist and the therapist who is reviewing the request for new equipment. DMA does not allow the evaluating clinician to informally contact the prescribing clinician. If the evaluator needs additional information, this is noted in writing and then mailed to the equipment vendor who must then seek out the prescribing clinician to provide the additional documentation. This process results in unnecessary delays and loss of clinician time spent "fighting the system." As Beth Gray-Nix remarked, *"There's a cost involved, I cannot tell you how many clinical hours are wasted writing letters, going to hearings, and fuss-budgeting over where we could possibly find the money to pay for things."*

Location of Service Restricts Access

As noted earlier in the report, where the consumer lives determines who pays for DME. If the person lives in a rehab hospital or nursing home, most DME is to be paid for by that site. If a person lives in a community based group home, DMA pays for it directly. The result of moving the burden of financing

from DMA to skilled nursing facilities and rehab hospitals has meant less access to equipment by the patient. Tim Sindelar, an attorney from the Disability Law Center, described a particularly poignant case: *"Now, my client who was forty-two years old, he sat in the nursing home…He needed a power chair. He had a power chair as a loaner. It wasn't very good. Didn't fit him right. In fact, the nursing home had to take it away from him, because he kept falling out of it. So he was trying to get his power chair approved by the Division. Six months, seven months, eight months, a year, a year and a half he sat in that room. And this was a real sociable young guy. Just had major mobility problems. Liked to be out in the community. Liked to be out dealing with the other residents in the nursing home. But he sat in his room day after day after day, except for the few hours that some staff person could come by. And he did that because the Division sits on its hands about a policy that they know is wrong, and is harming people."*

Capped DME Benefit in Private Insurance

Several testifiers noted that accessing DME and medical supplies through their managed care organization was especially challenging. Sonia Perduta-Fulginiti spoke on the need to eliminate these arbitrary caps. *"It is imperative that the health insurance coverage of DME prosthetics, augmentative communication devices, and other assistive technology be consistent with other medical treatment decisions. There can be no arbitrary cost limits placed upon these types of medically necessary devices based solely on disability and long-term health care need status."* Barbara Chandler noted that these caps also compromise access to hearing aids. *"Hearing loss is the single most prevalent disability among all elders. And yet, we have HMOs, we have insurance companies that have barriers, or I should say caps—the caps are the barriers—that would limit someone to five hundred dollars. You cannot buy a decent hearing aid for five hundred dollars…If you wear two hearing aids, you are only allowed to buy one every two years. And I compare this to buying your eyeglasses. You are allowed to get two lenses when you need them. When you wear two hearing aids, you should be allowed to get two hearing aids."*

Dual Eligibility

Two vignettes regarding the difficulty of access when the consumer is dually eligible were particularly compelling. Beth Buczko, a registered nurse with the Association for Community Living, described her difficulties accessing medical supplies for a person who had been previously institutionalized. This woman has a complicated enteral regimen using both g-tubes and j-tubes for nutrition. These feeding tubes are no longer provided at adequate levels. At one point, Medicare provided 24 tubes per year, and now only six are provided. The DMR provider pays for the additional tubes. This circumstance is particularly revealing given that even the narrowest definition of medical necessity would include feeding tubes.

The second vignette concluded the testimony from the hearing. Patrick Trainor from Billerica, MA described his efforts to get a new wheelchair for his daughter, Brea. Following the hearing, staff of the Governor's Commission investigated his complaint and found that indeed Brea has not had a new

wheelchair for ten years, and Medicare has denied a new one in the past year. If Brea's only insurance were Medicaid, with its broader definition of medical necessity, accessing a new wheelchair would be difficult but not nearly as lengthy a process or as problematic.

A Father's Story

My name is Patrick Trainor. I'm from Billerica, Massachusetts, and I have a daughter who is a resident at Fidelity House in Methuen, Massachusetts. And some of the things I've been hearing here today, I could just multiply them all, as far as being authentic.

My biggest frustration at the present time happens to be a wheelchair, just like the rest. My daughter is now thirty-three years old, and we've had this frustration since she was seven years old. And now she's in a wheelchair that she got when she was around fifteen years old. The problem is that she has to have a special [molded seat]…because she's got two rods in her back….I have tried, and tried, and tried to get this mold replaced, because she's grown out of it. A thirty-three-year-old does not fit in a mold that's made for a fifteen-year-old. So now she's grown out of the mold, so they have said we will replace the mold….But now, try to put a mold that's made for a thirty-three year old into a fifteen-year-old's power chair….My frustration is that they won't pay for that new wheelchair….But I asked the question. I said look, what do I do? Is there some way I can get an appointment with the Governor? Because I don't think the Governor knows what's going on in this state with these people pushing people around like this.…She's had her leg broken once. She's had her ankle broken once. And it's from falling out of the faulty equipment. Because when the chair tips over—she's tied in. And when that chair goes over, she falls with the weight of the whole chair on her back. So everything's pushed her face into the ground. The next time she fell out of that same chair because it was unstable, she fell out one side. Now remember, her legs are strapped into this chair. Now she goes one way, the chair goes the other, so it twists her. So her ankle gets broken. Her leg—I don't know how she got her leg broken. We'd like to get to somebody who could change the system, or correct things so that at least you could put your child into somewhere where you know they will be safe, or where you know the equipment will be provided.

C. Strategies for Improving Access to Assistive Technology and Durable Medical Equipment

Throughout the hearing clinicians, advocates, and family members urged the Commonwealth to improve access to assistive technology and durable medical equipment by persons with disabilities. The strategies for accomplishing this goal targeted five areas:

- Improve multi-agency collaboration.
- Expand state subsidized coverage for AT and DME.
- Improve communication between DMA, the user, and his or her prescribing clinician.
- Train DMR staff to better assist staff and consumers to access needed evaluations and equipment.
- Expand access to AT Centers at DMR developmental centers to include all persons receiving DMR services.

Improve Multi-Agency Collaboration

Two persons who testified at the public hearing and several focus group participants noted that in order to improve access to AT and DME, better collaboration among the state's health and disability agencies was essential. One testifier suggested that a time limited group be implemented that would have representatives from both state agencies and providers. The mission of this task force would be to:

- Evaluate access to equipment including the waiting period, denial, and appeals.
- Develop a systematic approach to informing and training DMR and provider staff about what is available and what the steps are to access equipment.
- Develop a prompt and speedy complaint process.

Expand State Funded Coverage of AT and DME

Most testifiers noted that inadequate funding hampered access to AT and DME. Several speakers advocated for support of particular legislation to improve access to DME for those who have private health insurance. Others advocated for expanded coverage by eliminating the regulations that functionally restrict access to those who live in facilities that are to receive their DME through their facilities. Tim Sindelar pointed out that DMA mandates that the reimbursement rate from facilities covers all DME needs. However, the rate set in a skilled nursing facility (SNF) often will not adequately cover the price of expensive equipment like a power wheelchair, and therefore an individual will not receive one. Finally, there were multiple calls to broaden the definition of "medical necessity" to include quality of life considerations.

Improve Communication between DMA, the User, and His or Her Prescribing Clinician

During both the public hearing and the focus groups, there was consensus that communication between DMA and users of DMA funded services was inadequate. Recommendations for change include:

- Establish an ombudsperson to facilitate complaint resolution.

- Allow flexible communication including phone calls and e-mail between the clinician that is evaluating a request for equipment and the prescribing clinician.
- Develop clear standards of medical necessity.

Train DMR Staff to Better Assist Consumers and Families to Access AT and DME

Several testifiers noted that often families and direct care staff do not know what is needed or where to go to find equipment. Several clinicians including Adria Hodas and Susan Rushfirth suggested that DMR and provider staff need training in order to assist families and consumers to access AT and DME. Suggested topics for this training include:

- How to enhance understanding of AT and DME.
- How to identify when equipment is not meeting a person's needs.
- How to advocate for new evaluations and equipment.

It was also recommended that staff and families be trained so that some basic repairs such as tightening wheelchair brakes could be done without calling DME vendors.

Expand Access to Assistive Technology Centers Currently Housed at the DMR Developmental Centers

Both at the focus groups and at the hearing there were recommendations that each of these centers be funded adequately so that all DMR consumers, regardless of where they live, have access to these high quality AT resources.

One aspect of the hearing that was particularly difficult was the realization that each situation described was **not** about someone who was ineligible for help from the government. Instead, every vignette relayed was of a person who **had** state-funded health insurance and often other supports as well. This realization, that the essential problem was not one of absence of help but woefully inadequate and poorly managed help, was further demonstrated by the recommendations made by the testifiers. Each suggestion made was reasonable: streamline the current bureaucracy, expand access to vital technology, and enhance the communication and sense of partnership between those who approve payment and those who rely on AT and DME.

V. Recommendations of the Governor's Commission on Mental Retardation

Our society has made tremendous progress in articulating a public commitment to the inclusion of persons with disabilities in our communities. Public policies to promote accessible public transportation and accommodations, employment opportunities, community based living, provision of appropriate health care, and financial security have been heralded achievements of the past twenty years. Public commitment to provide the required intensive (and at times expensive) levels of support and caregiving needed by persons with mental retardation and other disabilities has also been sustained. Part of the array of supports needed by some of these individuals is assistive technology and durable medical equipment. Technological innovations have redrawn the landscape of what is possible for persons with disabilities with respect to their capacity for more independent functioning.

Our study of the extent to which such technology is efficiently and effectively accessed by persons with disabilities and their care givers yielded a sobering conclusion—there are far too many obstacles to timely access to and payment for needed technology. Our recommendations are crafted to address some of these obstacles, but as is true of any effort to reform public policy and practice, these recommendations are only helpful if they are matched by a commitment on the part of public officials to squarely address this problem and muster the resolve to correct it.

The Commission has determined that there are five key problem areas regarding access to AT and DME. Specifically, the Commission makes the following recommendations:

Problem 1

The number of people with disabilities who would benefit from AT and DME has increased dramatically in the past decade. Reform of the funding system will not resolve the problem of access unless it is accompanied by a significant increase in funds.

Recommendations:

- Increase funding for AT and DME.
- The Commonwealth should explore amending one of the current Home and Community Based waivers to include additional access to funding for non-medically necessary AT. The expansion of the waiver would only be beneficial if it is a true expansion rather than a cost-shift of state dollars from one agency to another. Nor should this expansion be limited to persons with mental retardation but should include other disabilities as well.
- In addition, the Executive Office of Health and Human Services should conduct a cost-effective analysis to consider the following issues:
    1. What is the impact of appropriate levels of AT and DME on a person's health care expenditures? How is the utilization of treatment affected? Does the frequency of repair and replacement change? Are secondary conditions prevented?
    2. Similarly, how do appropriate levels of AT and DME impact access to paid work?

Problem 2

People with similar disabilities who receive Medicaid have different levels of access to equipment and technology depending on where they live.

Examples

- Residents of nursing homes may not be able to access helpful AT and DME that are available to other individuals with disabilities. The rationale—that such costs should be borne by the nursing homes—may once have been reasonable, given the limitations of then available AT and DME. Now, however, such policies are a significant impediment to access.
- Some especially high quality DMR services are available to only a single DMR facility or Region. Such inequity exists despite the fact that the relevant licensing and funding systems are exactly the same.

Recommendations

•Reform Medicaid regulations governing AT and DME funding such that support is provided according to what people need rather than where they live.

•Replicate throughout the Commonwealth exemplary local programs that provide superior clinical and AT support (e.g. the DMR Region 3 REACH Clinic, the equipment loan programs at the Fernald Developmental Center).

Problem 3

Increasing dual eligibility of persons with disabilities for Medicare and Medicaid has paradoxically decreased access to AT and DME for many people.

Explanation

Over the past 20 years, thousands of citizens with disabilities and Medicaid have been also enrolled into Medicare; up to 70% of adults who have mental retardation are now "dually eligible." This enrollment effort was intended to increase federal funding for necessary services. Unfortunately, the effort has had unintended consequences. Access to DME resources through Medicaid is now unnecessarily delayed by the requirement that individuals first submit time-consuming, usually fruitless applications to Medicare.

Recommendation

•Remove regulatory barriers to efficient access of Medicaid and Medicare funding by people with dual eligibility (e.g., allow vendors to bill Medicare and Medicaid in a manner that permits a timely response to consumer requests).

Problem 4

Procedures for reviewing recommendations of clinicians appear to be inefficient, difficult to understand, and unnecessarily slow, resulting in seemingly arbitrary delays in approving legitimate requests for DME.

Examples

- Even highly experienced clinicians who are familiar with DMA procedures frequently have their requests for equipment denied or returned for more information.
- There appears to be substantial variability in the application of review criteria (e.g., seemingly minuscule differences between successful and unsuccessful applications, little consistency in the nature of the requests for more information).
- In this age of electronic communication, clinicians are typically required to communicate with DMA via mail, another source of seemingly unnecessary and arbitrary delay.

Recommendations

•Establish clinical standards for DME through a collaborative effort between DMA, consumers, and expert clinicians.

•Make expeditious use of modern telecommunication procedures in processing of funding requests.

•Establish an ombudsperson program with DMA that will focus on facilitating access to equipment and supplies by assisting consumers to communicate effectively with the Division. One purpose of this program will be to collect and track all types of complaints and assist DMA with solving the systemic barriers to access.

•Establish a DME advisory board comprised of consumers, advocates, DME suppliers, and clinicians. The purpose of this board will be to help analyze the systemic complaints brought to its attention by the ombudsperson as well as make recommendations for reform.

Problem 5

Barriers created by the previously cited funding and process problems are exacerbated by uneven awareness of AT and DME needs and availability on the part of consumers and service providers.

Recommendations:

- An assessment of AT/DME needs should be included during DMR intake and transition to adult services.
- Significantly enhance access to relevant training for DMR and provider staff.

Concluding Comments:

The public hearing was an emotional one for the audience and Commission members. Rarely during a Commission hearing have the stories told been so poignant and revealed such inadequate efforts by the Commonwealth on behalf of its most vulnerable citizens. The recommendations made by the Commission are fueled by a sense of urgency and recognize that people have been waiting for years for reform. The Commission hopes that those who attended the hearing and read this report will also be moved: moved to action, to a commitment to fairness, to a necessary expansion of service.

Appendix 1

State	Benefit	Population
AK	Specialized Medical Equipment	MR/DD
AL	Specialized Medical Equipment	MR/DD
	AT	
AR	Adaptive Equipment	DD
CA	Specialized Medical Equipment	MR/DD
CO	AT	MR/DD
CT	Specialized Medical Equipment	MR/DD
DC	Specialized Medical Equipment	MR/DD
DE	Specialized Medical Equipment	A/D
FL	Specialized Medical Equipment	A/D
GA	Specialized Medical Equipment	MR/DD
HI	Specialized Medical Equipment	MR/DD
IA	Specialized Medical Equipment	PhysDis/DD
ID	Specialized Medical Equipment	A/D
IL	Specialized Medical Equipment	MR/DD
	Adaptive Equipment and modification	MR/DD
IN	Adaptive Aids and devices	A/D
	AT	MR/RC
KS	Adaptive Equipment	MR/DD
KY	Specialized Medical Equipment	MR/DD
	Specialized Medical Equipment	TBI
LA	Assistive Devices	MR/DD
MA	**NA**	
ME	Adaptive Devices	MR/DD
	Medical Equipment and Supplies	TBI
MI	Enhanced medical equipment & supplies	DD
	Specialized Medical Equipment	A/D
	Specialized Medical Equipment	MR/DD up to age 18
MN	AT	MR/RC
	Specialized Medical Equipment	ABI
MO	Adaptive Equipment	MR/DD
MS	**NA**	
MT	Specialized Medical Equipment	A/D
NC	Specialized Medical Equipment	MR/DD
ND	Specialized Medical Equipment	A/D, TBI
NE	Specialized Medical Equipment	A/D
NH	**NA**	
NJ	**NA**	
NM	**NA**	
NY	AT	MR/DD
OH	AT, Home medical equpment	AD
OK	Specialized Medical Equipment	A/D, MR/DD
OR	**NA**	
PA	Specialized Medical Equipment	Adults with Disabilities
RI	Specialized Medical Equipment	MR/DD
SC	Specialized Medical Equipment	A/D
	AT	MR/DD
SD	Medical Equipment	A/D?
TN	Specialized Medical Equipment, AT	MR/DD
TX	Adaptive Aids	MR/DD,A/D
	Specialized Medical Equipment	Current ICF-MR
UT	Specialized Medical Equipment	MR/DD
VA	Specialized Medical Equipment	MR/DD
VT	Assistive Devices and modifications	A/D
WA	AT & Specialized Medical Equipment	A/D

	Specialized Medical Equipment	MR/DD
	Specialized Medical Equipment	DD in NF
WI	Specialized Medical Equipment	A/D
WV	**NA**	
WY	Specialized Medical Equipment	DD

Appendix 2

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